

Examining Services Available to Greek Parents of Children with Autism Spectrum Disorders (ASD)

Eirini Veroni
Centre for Education Studies, University of Warwick
E.Veroni@warwick.ac.uk

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1. Theoretical Considerations

This research note documents the challenges that Greek parents encounter in their everyday efforts to provide for their children with autism spectrum disorders (ASD), along with the ways that can be used to enhance partnerships between these parents and professionals such as children's psychiatrists, psychologists and speech therapists. A plethora of research in the field of special educational needs (e.g. Gray, 2003; Hutton & Caron, 2005; Montes & Halterman, 2007; Tomanik, Harris & Hawkins, 2004) has discussed the difficulties faced by parents of children with Autism Spectrum Disorders (ASD)¹. This disorder will subsequently be referred to by its abbreviated form in this work. Glover-Graf (2011), for instance, postulates that parents of children with ASD are likely to experience strained marital and extended family relationships, social isolation, challenging educational arrangements, and a sense of grief related to the restricted opportunities for their children. In this regard, a

¹ Autism Spectrum Disorders (ASD), which include autistic disorder, pervasive developmental disorder and Asperger's disorder, are a group of neurodevelopmental disorders that are characterized by social and communication impairments as well as repetitive or stereotyped behaviours (American Psychiatric Association, 2000). Prompted by the increase in the prevalence ASD, it was recognized as a special needs category under educational laws numbers 1566 and 2817, enacted by the Greek parliament in 1985 and 2000 respectively.

diagnosis of ASD affects not only the diagnosed individual, but extends to include the entire family. Given that it is the parents who are often seen as the most influential agents on their children with ASD (Wang, 2008, Singer et al., 2012), some researchers (e.g. Beatson, 2008; Beckman, 2002; Prelock et al., 2003) have accentuated the salience of providing family-centred care by taking into account the ongoing interactions between families, and professionals. In Greece, the context of the current study, prompted by the increase in the prevalence of ASD, it was recognized as a special needs category under educational laws numbers 1566 and 2817 which were enacted by the Greek Parliament in 1985 and 2000 respectively. In 2008, a new educational law (number 3699) was introduced specifying that educational placements for children with ASD should be determined according to their cognitive, language and social development (Syriopoulou-Delli, 2010).

Previous empirical studies have explored the needs of children with ASD (e.g. Gena, 2006; Hitoglou et al., 2010; Kalyva, 2011; Makrygianni & Reed, 2010; Stampoltzis et al. 2012), the difficulties that Greek parents of children with ASD encountered, but fell short of seeking to offer practical steps to overcome the identified difficulties or unearthing the relationships between these parents and professionals. The contribution of the present research lies in the fact that previous research in Greece has tended to focus on the state of special education in the country from the perspective of special education teachers (e.g. Athanasiadis & Syriopoulou-Delli, 2010; Avramidis & Kalyva, 2007; Kokkinos & Davazoglou, 2009; Miller, Morfidi & Soulis, 2013). However, there is little evidence of research on the parents' perspectives regarding their views on the provision of disability services for their children in an era of severe economic crisis and austerity. This is a key differentiating factor between this study and several previous research projects.

Notably, the findings of studies conducted by Kalyva (2013) and Stampoltzis et al. (2012) showed that there was a noticeable lack of services offered to children with ASD in Greece, especially in terms of the quality of education and care. These studies found that the Greek government did not offer sufficient financial support either to parents of children with ASD or to professionals in the form of training and professional development, for instance.

Increasingly, many families in Greece face serious challenges in supporting their children with ASD, principally in terms of overcoming current financial difficulties due to the economic crisis and handling the lack of appropriate educational provision (Gena et al., 2006). Thus far, only a very limited number of empirical studies (e.g. Gena, 2006; Hitoglou et al. 2010; Kalyva 2013; Makrygianni & Reed, 2010; Stampoltzis et al. 2012) have been conducted in Greece to examine some contextual factors, including parents' involvement with children's learning, parent-professional co-operation, types of services offered in special education settings, the lack of public services and generally limited resources and educational provision for children with ASD.

Some researchers (e.g. Karim et al., 2012; Ridge, 2013) have argued that families and children with disabilities are worst hit when resources become limited. Hartas (2014) pointed out that many Western countries (e.g. the U.K., the U.S. and Canada) are facing difficulties that hinder the provision of quality services to children. These difficulties encompass the general climate of austerity, severe cuts to public spending and the crumbling of the welfare state. This author notes that in such circumstances, families' social problems become privatized and the onus is on individual parents to overcome structural problems aimed at tackling social inequality and child poverty (Hartas, 2014). A reduction in childcare support from the state has impacted most heavily on those families encountering the severest depths of poverty who, it is reported, are getting into debt and cutting back on essentials to try to sustain their childcare (Save the Children and Daycare Trust, 2011). Moreover, according to Ridge (2013), social care services are overwhelmed and the poorest children and families are bearing the brunt of the recession and of austerity measures. However, in a surveillance society in which the state is receding from its obligation to the polity, the privacy of family life should be guarded because it may be the last refuge where parents and other family members can still function as a "buffer" (when needed) between children and the state to protect them from exploitation and oppression. (Hartas, 2014 p. 135)

With the above in mind, the current study has to a small extent redressed the balance by disentangling the needs of parents to support their children with ASD and to find resources that improve their resilience especially in an era of austerity. In this

quantitative inquiry study, the following research question needs to be answered:
What are the Greek parents' views towards these educational and social needs of their children with ASD?

2. Methodological Design

A purposive sampling strategy (Patton, 2002) was adopted and the sample comprised seventy-four parents of children with ASD. The selection of parents who have children with a diagnosis of ASD was essential for the credibility of this research. The fieldwork took place in three special schools for children with ASD: one urban and two suburban of mixed socioeconomic-status (SES) and also three Centers for Differential Diagnosis and Support of Special Educational Needs (K E D D Y)² located in different areas of Athens in the Attica region of Greece. All these settings were selected because they had multidisciplinary teams that conducted assessments and supported children with ASD.

The parents deemed eligible to participate in the study were the biological parents of a child diagnosed with ASD, aged 7 to 17 years and enrolled in the state school system at either primary or secondary level. The two main groups of respondents have been included in the total sample, reflecting the relationship to the child who has an ASD.

These comprised 53 mothers (71.6%) and 21 fathers (28.4%). Most of the children with ASD were male. Such a high proportion of boys was not particularly unusual for a sample of people with ASD. Indeed, there were not statistically significant differences in the responses from parents of boys versus parents of girls.

²In 2000 with Special Education Law (L2817/2000), the Ministry of National Education and Religious Affairs established 54 Diagnostic, Assessment and Support Centers (K D A Y) in the capital cities of each prefecture in Greece. These centers provide diagnosis, assessment and support to all children mainly 3-22 years old and families who have difficulties. In each center, there is an interdisciplinary team, which consists of special teachers from different educational levels and professionals (social worker, psychologist, child-psychiatrist, physiotherapist, speech therapist, etc). These centers according to their constitution can provide early childhood intervention services for young children and parents who need help. The interdisciplinary team undertakes the assessment of the child, provides support and counseling for the child and the family and designs the Individualized Educational Plan for each child. K D A Y became K E D D Y (i.e. Centers for Differential Diagnosis and Support of Special Educational Needs) under more recent law (Law 3699/2008, art.2), and the centers still provide support for various SEN diagnoses, including guidelines for teachers (MNERA 2008).

In all this totalled 58 children (78.4%), while 16 children (21.6%) were female. In total, 74 children aged from 8 months to 18.6 years ($M=11.23$, $S.D.=3.39$) were included.

All parents of children with ASD were asked to complete a questionnaire aimed at acquiring general background information about their experiences regarding ASD. Furthermore, these parents completed the Family Needs Scale which was devised for this study having been adapted from the Impact on Family Scale (Stein & Jessop, 2003), Family Needs Questionnaire (Siklos & Kerns, 2006) and the Professional Autism Needs Questionnaire (PAN-Q) (Keenan et al., 2007) already mentioned previously. This questionnaire was delivered to the participants by hand in order to maximize the return rate. The Family Needs Scale consists of nine items scored as: “not important”, “slightly important”, “important”, or “very important”. The internal consistencies of this scale were Cronbach’s $\alpha=0.61$.

This research complies with the guidelines of the British Educational Research Association (BERA, 2011). In the first place, an official approval was sought from the Special Education Department of Ministry of Education in Greece. The participants were also informed that their involvement was optional and they could withdraw at any time. Prior to the research, the participants provided their written consent and they were made aware of the nature of the research and the adopted approach. The participants also were informed that their cultural values would be met with respect and that their responses would be kept both anonymous and confidential.

3. Results

3.1 Parents' Needs

With regard to parents' needs, a descriptive analysis of family needs is presented in Table 1. More than half of the parents rated as “very important” having support with educational decisions (68.9%) child development, (68.9%) financial matters (74.3%) and access to public services (K E D D Y)³ (64.9%). In relation to accessing emotional support from parents of children with ASD and needing reassurance about harbouring negative feelings regarding a child’s challenging

³ See footnote 2.

behaviours (e.g. odd mannerisms, stereotyped behaviours) parents were equally divided into those who rated this as “important” (40.5%) and “slightly important” (40.5%). Around half of parents (48.6%) rated counselling as “important” for them and their spouse. Roughly one third of parents (41.1%) rated the development of a social network as “important” and “very important”.

Table 1
Frequencies of parents’ rating of support

Parents’ needs	Slightly Important		Important		Very Important	
	<u>Frequency (f)</u>	%	f	%	f	%
Financial support	6	8.1	13	17.6	55	74.3
Educational decisions about the child	2	2.7	21	28.4	51	68.9
Support concerning autonomy of the child	3	4.1	20	27	51	68.9
Assistance from public centers (K E D D Y)	7	9.5	19	25.7	48	64.9
Help in care and positive handling of problems	7	9.5	26	35.1	41	55.4
Counselling	13	17.6	25	33.8	36	48.6
Development of a social network	13	17.8	30	41.1	30	41.1
Reassurance regarding negative feelings about child's challenging behaviours	29	39.2	30	40.5	15	20.3
Emotional support from other parents of children with ASD	30	40.5	30	40.5	14	18.9

N=74 Parents of children with ASD

4. Discussion and Implications

Although it is work in progress, the purpose of this study is to examine basic parental needs and the difficulties experienced in supporting children with ASD. The presence of a child with ASD creates challenges to family life but it also impacts specific inter-familial relationships. In general, parents have basic requirements in terms of financial support, with educational decisions, concerning the autonomy of their child and they seek assistance from public Centers for Differential Diagnosis and

Support of Special Educational Needs (K E D D Y)⁴. It is essential therefore to support a reorganization of parents' lives which would result in the necessary adaptations and also ensure that the needs of their entire family are met (Van Riper, 2007 p. 124).

An interesting finding which must be paid attention to concern the difficulties that parents experienced in finding an appropriate educational setting for their children with ASD. This trend may be the result of the implementation of Law 3699 which gives Greek parents the right to choose between special or mainstream education for the child. Some recent studies (e.g. Makrygianni & Reed, 2010; Papageorgiou & Kalyva, 2010; Syriopoulou Delli et al., 2012) showed that the Greek educational system seems to have a difficulty including pupils with ASD in mainstream schools, because of the demanding curriculum content and the lack of appropriate teaching accommodations and trained personnel in both primary and secondary education. Greek parents were found to have experienced unhelpful bureaucracy and a general lack of taking responsibility which could be said to characterise the attitude of the Greek education system (Zoniou-Sideri, 2011).

This study revealed parents' voices for better services towards their children with ASD's educational and social needs. They struggle to obtain quality in education and services, being faced with the absence of necessary technical infrastructure, understaffing in schools, lack of funding, covert or overt practices of acceptance and/or rejection of people with disabilities in the educational system (Loukisas & Papoudi, 2016).

A remarkable result emerging from this study is the financial strain of raising children with ASD as experienced by Greek parents. This may be a result of the Greek National Insurance Service which covers only a small part of the expenses. Parents' need for financial support has also been reported in a number of other studies (e.g. Makrygianni & Reed, 2010; Miller et al., 2013; Syriopoulou-Delli et al., 2012). There is good evidence that the financial burden of care for a child with ASD is very substantial, although precise estimates that incorporate all associated costs are not yet

⁴ See footnote 2.

available. There is clearly an urgent need for addressing this especially during a period of austerity when already overstretched welfare services are being further curtailed. This is consistent with Ridge's (2013) study which showed that cuts in social security benefits had a severe financial impact on most families, in particular, those with children with special educational needs (SEN)⁵, who have been losing out in relation to having their educational, social and physical needs met.

Overall, this study provides valuable information regarding the challenges of seventy-four parents with children with ASD using survey data. It may assist parents and professionals to establish effective channels of communication to support the educational and social needs of children with ASD. Ultimately, then, there is a strong need for a comprehensive state-maintained support system in Greece that caters for parents' needs and expectations for their children with ASD. This system could consist of a variety of professionals (i.e. teachers, services providers, educators, financial advisors) that could meet the individual needs of families struggling to help their children with ASD. More empirical studies are needed to clarify the salience of partnership and communication between professionals and parents. This can serve as a benchmark to improve the services offered to children with ASD.

⁵ Formalised in the *1981 Education Act*, 'SEN' is the official term used in England in educational settings to refer to children who are involved in special education (Department for Education (DfE), 1981). Children with SEN are those who have "a learning difficulty which calls for special educational provision to be made for them" (DfE, 2014, p. 6). SEN includes communication and interaction difficulties, cognition and learning difficulties, emotional, social and behavioural difficulties, and sensory and/or physical disabilities (DfE, 2014).

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Appendix: Family Needs Scale

With regard to my child's care, I need:

(Please tick as appropriate)	Very Important	Important	Slightly Important
Help in care and positive handling of problems			
Educational decisions about my child			
Support concerning autonomy of my child			
Emotional support from other parents with ASD children			
Reassurance regarding negative feelings about my child's challenging behaviours			
Counseling for myself and my spouse (i.e., marital strain)			
Support with developing a social network			
Financial support (i.e., from government)			
Assistance from public centres (K E D D Y)			